

The Childhood Bereavement Network

London, UK

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Research developments, coupled with an increasing body of experience across palliative care settings and adult bereavement services, have led to greater awareness over the last 20 years of the needs of bereaved children. This, in turn, has resulted in the emergence of a range of information, guidance and support services for children, young people and their families.

By 1998, the UK services were sufficiently developed and diverse for people to see the need for greater co-ordination and co-operation. Under the aegis of the National Association of Bereavement Services, funding was applied for from The Diana, Princess of Wales Memorial Fund to develop a national network to link together individuals and organisations working with bereaved children and families throughout the UK. In partnership with Marie Curie Cancer Care, a conference and series of consultation meetings were set up, out of which the Childhood Bereavement Network (CBN) developed. This is now a national multi-agency network of organisations and individuals who work with bereaved children and young people.

Since 1998, the CBN has hosted more than 100 networking and training events, including three national conferences, and a further 60 will take place by 2006. Participants have recognised the value of getting together to share information -

'it keeps us informed in our isolated work' - to develop good practice, make local connections with other practitioners and services, and champion bereaved children and young people's needs.

The CBN was launched as a national subscription scheme in 2001 and today is hosted by the National Children's Bureau. Our membership (now over 270) ranges from national charities, hospice and palliative care social workers, to schools, health visitors and researchers. Representatives from all the major UK bereavement care providers are included on our consultant panel and various working groups. We also incorporate a growing number of community based 'open access' services, which work with children and young people whatever the cause of their bereavement. These were mapped by us in 2003 on behalf of the UK government and the directory can be viewed at www.ncb.org.uk/cbn/directory.

The aim of mapping services and sharing information across the Network is to increase access to services. 'As we only offer our service to clients of the hospice, it is useful to be able to signpost to other agencies when we are so frequently asked for help', wrote one subscriber. Yet there are still areas of the UK where there is little provision for bereaved children and young people. Part of the CBN's current work is the encouragement of new, locally appropriate

services by arranging regional seminars, offering consultancy, and producing a tool kit.

However, our work is not just about new services. We are tapping the Network's wealth of experience and insight in a series of seminars, bringing practitioners together to expand our *Guidelines for Good Practice in Children's Bereavement Services* into useful principles on areas such as safety, accountability and equality. This model of consultation also informs policy work. A priority for us is to ensure that policy makers at national and local level acknowledge that bereavement can be a risk factor for children and we have recently published a policy briefing paper setting out the key issues.

CBN subscribers believe that information, guidance and support for bereaved children and young people should 'be responsive to the child's needs, views and opinions' and so we are encouraging the involvement of young people across the Network. We have begun to produce our own resources, such as three participatory videos about children's experiences of bereavement, and a set of postcards for them to use as prompts in seeking support from those around them. Together with Winston's Wish and the Laura Centre, we are also supporting our members in developing special services for parents of bereaved children.

All of the CBN's work is dedicated to improving the range, quality and accessibility of bereavement support for children, young people and their families. For more information about our work and programme of meetings, or to join, please contact CBN, 8 Wakley Street, London EC1V 7QE, ☎ 020 7843 6309; email cbn@ncb.org.uk; website www.ncb.org.uk/cbn BC

O B I T U A R Y

Elizabeth Kübler-Ross 1926-2004

Psychiatrist who pioneered work with the dying



It was in the mid 1960s, in Chicago, that I first met Elizabeth. I sat behind a one-way vision screen while she was talking in a caring way to a patient

with late stage cancer about his coming death. Somehow she had managed to make the extraordinary and fearful topic of his death into an ordinary topic, which could be discussed sensibly and without fear. It was this capacity that enabled her to carry out a groundbreaking study which was later published as *On Death and Dying* (London, New York: Tavistock/Routledge, 1969). This book did more than any other publication to draw attention to the psychological needs of people suffering life-threatening illness and it helped to prepare the ground for the hospice movement and the revolution in palliative care that was to follow.

Chicago was an exciting place to be at that time. Elizabeth's professor of psychiatry was Knight Aldrich, whose little-known paper, 'The dying patient's grief' had prompted her own work in the field. Others whom I met included Bruno Bettelheim and Paul Tillich, both of whom were deep into the psychological and spiritual issues surrounding death. I had been invited to give a paper on bereavement in which I described Bowlby's stages of grief. This idea appealed to Elizabeth and emerged in her own 'stages of dying'. Such was the popularity of her writings in the USA that many later writers attributed the stages of grief to Kübler-Ross.

Elizabeth always blamed her peers for the academic isolation in which she worked but in fact she was widely respected and it was she who rejected

offers of collaboration and support from the medical fraternity. Consequently she played little part in the developing hospice movement and in the mid-1970s moved to California to set up her own community 'Shanti Nilaya'. By this time she had become part of a religious cult involved with spirit guides, ghosts and a fraternity who seriously damaged her reputation. Her own death, following a series of strokes, was protracted and she complained that God had kept her waiting far too long.

I shall remember Elizabeth as a courageous little lady who cared passionately about her patients. She helped to break several of the taboos that surround death and, in her later work, included people with AIDS and children faced with death and bereavement. BC

Colin Murray Parkes